

SB 1014  
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Good morning honorable members of the Public Health Committee. I would like to thank you for the opportunity to speak in support of SB 1014.

My name is Jennifer Gilloren and I live in Beacon Falls. I am NOT a doctor, politician, lobbyist or even a cancer survivor. I have not endured months of chemotherapy or days of waking up from sedation screaming because I did not know where I was. I have not woken up to find my lost hair all over my pillow or my face so swollen that I could not open my eyes. I have not been forced to live with tubes hanging out of my chest, screaming each morning as I was forced to bathe and get dressed.

I AM the mother of a cancer survivor and witness to the miracle of bone marrow donation. I am here today not to explain the statistics of bone marrow transplants or the financial ramifications of this bill but to give you a glimpse of what this process means to the patient and their family. I am here today to tell you what it feels like to be told that someone you love will probably die without a bone marrow transplant. I am here today to tell you that, if passed, SB 1014 WILL save someone's life. Passing this bill will allow local communities and organizations to organize more wide spread donor drives and raise awareness of a treatment which is widely misunderstood.

My daughter Carsyn was diagnosed with acute mylogenous leukemia when she was fourteen months old. Less than twenty four hours later she was admitted to Connecticut Children's Medical Center and did not leave her room for five weeks. We were told that Carsyn's form of leukemia was very aggressive and she would need a bone marrow transplant if we were to hope for a cure. I remember hearing the doctors say that Carsyn had a sixty percent chance of survival but all I could comprehend was that my baby had a forty percent chance of dying. I sat there nodding my head but I didn't even know what bone marrow was, let alone what a transplant entailed. We were told that there was only a 25 percent chance that Carsyn's older sister would be a match so we would probably need to search the National Bone Marrow Donor Registry.

On December 10, 2004 Carsyn was admitted to Boston Children's Hospital for preparations for her bone marrow transplant. For the next week, she underwent twice daily total body radiation sessions and doses of chemotherapy so powerful that it would kill her entire immune system and all of her blood cells. The hope was that this would destroy all of the leukemia cells as well. On December 16th, Carsyn was given a bone marrow transplant with healthy donated cells. During the following agonizing weeks, we watched our daughter struggle through each day, literally fighting for her life. We held her up while she vomited hour after hour until she popped blood vessels in her eyes. We watched helplessly as the number of IV tubes increased to carry the growing load of antibiotics, high blood pressure medications and morphine. We watched our happy nineteen month old become increasingly depressed, not wanting to eat, let alone play. Finally, on February 11, 2005 Carsyn was well enough to return to Connecticut. On the day she was released from the hospital she was so weak that she could not even walk - her five year old sister had to hold her up while she walked to the bed.

I still look at my daughter everyday and make a conscious effort to push away the thought of losing her. She sings and dances around the house with her sister as if the world is a perfect place. She is full of so much compassion and kindness that she can't contain it. I remember a day when Carsyn was at her lowest emotionally and physically but she forced a smile when her grandparents came to visit. They said to me that she would be OK because she was too amazing and special and important to this world for anything to happen to her. At that moment I realized that it didn't matter who she was or how much she had to offer the world. She could die anyway. Every child with cancer is special. These children endure so much yet their souls find a way to flourish and grow. When you walk into the Jimmy Fund Clinic at Dana-Farber Cancer Institute for the first time, you can't help but notice all the little bald heads. But then you stop and look around

and notice that they are not crying or whining or feeling sorry for themselves. They are smiling and playing on the computer and doing crafts. They are making friends and living life. Their illness is just a part of their lives - it just is what it is.

Carsyn is one of the lucky ones. Her sister, Avery, was able to be her bone marrow donor. Childhood cancer kills more children than any other disease - more than AIDS, asthma, diabetes, cystic fibrosis and congenital anomalies combined. More than 25,000 people in the United States are diagnosed each year with a life threatening disease that requires a bone marrow transplant. Nearly 70 percent must find an unrelated donor. Fifty years ago, childhood cancer was almost always fatal but today, with treatments such as bone marrow transplants, three quarters of children survive.

I am here today to support SB 1014 because, if passed, it will allow doctors to open a dialogue with their patients during routine exams about the benefits of becoming a donor. It will allow local organizations to concentrate on much needed public awareness programs to educate the community, not only on how to become a donor but how simple the process of donation is. When you are a donor, you are not giving up anything that your own healthy body can not readily replace. Insurance companies have infrastructures in place already that could easily absorb the processing of testing as well as the relatively small cost to them. I feel that it is the responsibility of these companies to cover this testing in much the same way that they cover the cost of chemotherapy and radiation treatments. I also feel that by involving these companies, the process will be streamlined and related costs will eventually lessen. Although I recognize that a specific donor who is tested may not benefit a patient covered by the same company, the company may have the benefit of finding a donor brought into the system by another insurance company to match their patient.

Families and patients battling cancer are already incurring financial hardships such as medical expenses, travel and lodging during treatment and the inability to work. Many families who can not find a match on the National Bone Marrow Donor Registry take on the additional task of raising money for donor drives in the desperate hope of finding a match, even though it is unlikely that their drive will have any benefit to them. Currently, it is the donor's responsibility to pay for their own testing, if the coordinators of drives can not raise enough money (approximately \$60-\$90 per person). This simply is an unfair and selfish burden to place on them. Cancer patients need to concentrate on surviving, not raising money.

On May 21, 2005 my family held a bone marrow donor drive in New Hampshire to celebrate Carsyn's second birthday. We were able to add 102 new donors to the registry. I firmly believe that had we not spent so much time worrying about raising funds, we could have spent more time raising awareness and ultimately brought in more donors. On January 19, 2006, I had the honor of speaking in support of a bill similar to the one before you today (HB 1452) at the New Hampshire State Legislature. The bill was passed in June 2006 and New Hampshire now joins other states such as MA and RI who currently have bills requiring insurance companies to pay for donor testing.

Please support SB 1014. This bill is not a QUALITY of life issue, it is a RIGHT to life issue. You have the opportunity today to help someone save a life.

Thank you for the opportunity to speak today and for your consideration of this bill.